

## House Bill 5666

Seven hundred and eighty one days from today. Does that seem to you to be very far into the future? Or, is it just a mere moment away in time and space? Your answer to that question will depend upon your individual frame of reference and how you feel about the event that awaits you at the end of the road. For me, it will be here in no time, before the blink of an eye in fact.

Why? Well, that is the exact number of days left between today and the day my son Aaron will be 21 and “age out” of the State of Connecticut educational system. Aaron is one of a growing number of individuals diagnosed with Autism Spectrum Disorder. He functions on the higher end of the range of this disorder, otherwise known as Asperger’s Syndrome. And, his IQ is such that when he reaches that important milestone age, he will no longer qualify for continued services from the system we have relied upon for the last 13 some odd years.

And services are the name of the game for us. Without them Aaron will surely suffer immeasurably and potentially lose many of the gains we have fought so hard to make along the way. So what are our choices? What can we do today to deal with this unfortunate reality? Many well meaning friends have tried to counsel me on how to get Aaron continued access to those valuable services. They say that my best option is to find a way to make sure his final test scores fall just below the mandated cutoff. “Don’t give him his meds the day of the test,” I was advised. “Keep him up all night so that his score will suffer,” they urged.

Certainly you will all agree that these were outrageous suggestions and I never gave any of them a moment of serious consideration. But up until now what other choices have there been in our fair state? Unfortunately none. I have fought long and hard to help Aaron, and the world at large, to accept my son for the wonderfully unique person he is. I will not cloak his condition in lies and misrepresentations to “beat the system” to get him the services that he needs and deserves just because he has crossed some chronological line in the sand to adulthood. However, the fact remains that it has taken a village to come as far as we have in our quest to help him become an independent member of our community. But he is not there

yet by any measure and certainly won't be there seven hundred and eighty one days from now. Age 21 is someone else's magic number, certainly not ours.

Thoughts of day 782 keep me awake more nights than I care to think about. If you knew what I know, you might stay awake as well. Rest assured though that ignorance of my reality will not be bliss because someday he will live among you for better or worse. I can promise you that. The question for all of us is, will he live well beside you as an independent contributing neighbor and co-worker or will he end up in the penal or mental health system as a financial burden and loss to society? It will not be my choice. It will not be Aaron's either but it may be inevitable if we do not do something now to provide an alternative. With the proper supports and services I am confident that Aaron will continue to make gains toward true independence and become a fully contributing member of society.

The pilot project for Adults with Autism Spectrum Disorders Without Mental Retardation has placed Connecticut front and center in a national movement to support the ever growing number of citizens on the spectrum. After much hard work at the legislative level, we have become enlightened and the state of Connecticut now has a Bureau of Autism Spectrum Services within our newly renamed Department of Developmental Services. As a member of the original steering committee for the pilot project for Adults with Autism Spectrum Disorders without mental retardation and now on the Advisory Board for the Bureau, I have seen firsthand that we can make a difference for this population and we can do that cost effectively for the state and its constituents. I am proud of my contributions within this movement and I am proud of the state of Connecticut for their support.

Now it is time for the next phase of the project – the establishment of a second pilot project based in Hartford. We have made it work downstate, I have seen it with my own eyes. We must have additional financial support to extend the program's reach to more of our fellow citizens with Autism Spectrum Disorder. We must work hard to be sure that we are ready for the growing numbers that will cross that line in the coming years.

781 days. For over 18 years I have thought of that day as an abstract. I prayed with all of my heart that much would change before then and somehow the future would become crystal clear – or perhaps just not the deep opaque that has clouded my dreams for years. The pilot project is beginning to provide the light to the future for individuals like my son. Please lend you support to Bill 5666 and finance an extension of the pilot program into the Hartford area.

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